

# How Does Diabetes Affect Daily Life? A Beyond-A1C Perspective on Unmet Needs

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## Supplementary Data

### Files in this Data Supplement:

- Supplementary Appendix A
- Supplementary Appendix B

### APPENDIX A

Selected open-ended comments:

“The burden of good management encompasses so many things to me: in-range A1c, feeling physically well, not struggling with dangerous hypoglycemia or the risk of DKA during hyperglycemia, ability to live as close to a ‘normal’ life as possible.”

“An ‘artificial pancreas’ device would keep my blood sugar levels closer to the non-diabetic range— and this in turn would allow me to get real sleep for the first time in over two decades.”

“I have had diabetes for over twenty years, each year it seems to affect more areas of my life. I would love to have something that would stop the progression of damages to different parts of my body.”

“I’d like to understand how all different factors (different kinds of nutrition, exercise, stress, illnesses. . . ) affect my blood glucoses...examining that data together with blood glucose measurements is really hard.”

“Help with drug interactions. I take 25 different pills daily, some multiple times, over 4 sessions (breakfast, lunch, dinner & bedtime).”

“Keep my blood sugars under control; i.e., in range. The variability of life leads to huge variability in blood sugar levels, which makes life difficult.”

“I want to be less fearful of hypoglycemia and less dependent on family care for me during such times.”

“An insulin that doesn’t cause weight gain would be amazing. I have been unable to lose the 12 extra pounds I’ve been carrying since starting insulin, even with frequent, intense exercise and a strictly restricted diet... I still cannot lose that extra weight.”

### APPENDIX B – The Survey

#### Introduction

Thank you for taking this short but important survey!

On November 3 from 1pm-4pm EDT, the Food and Drug Administration (FDA) and the diabetes community will host an unprecedented event to discuss unmet needs in diabetes. As a community, our job is to present the numerous challenges we as patients face each day, and we need your opinions to be a part of this discussion! Please fill out this short survey to share your thoughts on what’s important to you when it comes to living with diabetes.

Your feedback will go directly to FDA and help influence the conversation on November 3.

Please answer the questions that follow as honestly as you can. Your answers could affect the way the FDA perceives unmet needs in diabetes, and ultimately, how it reviews the risks and benefits of new drugs and devices.

Let's begin!

#### Question 1

*Which of these statements best describes you?*

*If you are both a person with diabetes and a parent or caregiver of a person with diabetes, please answer on behalf of yourself.*

- I am the parent of a child or teen with diabetes
- I am the caregiver of an adult with diabetes
- I have pre-diabetes
- No diabetes

#### Question 2

*What kind of diabetes do you have?*

*If you are not sure, please choose the 'I'm not sure' option.*

- Type 1: (People who have type 1 are usually diagnosed as a child, teen or young adult. Typically they start taking insulin immediately or soon after)
- Type 2: (People who have type 2 are usually diagnosed as an adult. Many do not take insulin, but those who do usually start sometime after diagnosis)
- Latent Auto-immune Diabetes in Adulthood (LADA)
- Gestational: developed during pregnancy without prior diagnosis of diabetes. (If you had gestational diabetes and have since been diagnosed with another type, please select that type)
- I'm not sure which type I have
- I have another type of diabetes (please specify)

#### Question 3

*Of all the ways that diabetes affects you, which of the following has the greatest impact on your day-to-day life? Please select the three that have the greatest impact on you personally, in order of importance.*

MOST important impact of diabetes:

SECOND most important impact of diabetes:

THIRD most important impact of diabetes:

- Drop Down Choices: Difficulty managing your blood glucose; Hypoglycemia (low blood glucose); The time commitment and burden good diabetes management takes; Managing your diet; Focusing on work or school; Getting exercise; Sticking to the diabetes medication routine your doctor recommends; Managing your weight (losing weight or keeping weight off); Other people's perceptions and opinions about diabetes; Getting enough sleep or sleep problems; Other

#### Question 4

*Which types of diabetes medications do you take? Please select all that apply to you.*

- Insulin;
- Non-insulin injections (for example Bydureon, Byetta, Victoza, Symlin);
- Pills;
- No medications specifically for diabetes, just diet and exercise

#### Question 5

*Which of the following do you use as part of your diabetes management?*

*Please select all that apply to you. If you don't use any of these, select 'None of the above'.*

- A blood glucose meter
- An insulin pump
- A continuous glucose monitor (CGM) – these are devices made by Medtronic or Dexcom
- A pen for injecting insulin or another diabetes medication
- Diabetes-specific applications (“apps”) for your phone
- None of the above

#### Question 6

*How well would you say your diabetes medications and/or diabetes devices are working in terms of helping you manage your diabetes successfully?*

For this question 1 is ‘not working at all’ and 10 is ‘working very well’

- 1-10

#### Question 7a

*Are there things you would like to do (or do more of) that you don't do or that are difficult for you because of diabetes?*

- Open-ended

#### Question 7b

*For the activities that you listed above, are they things that you don't do or are they things that are difficult for you to do because of diabetes?*

- Don't do
- Difficult to do

#### Question 8

*Some people may experience other health complications while they are managing their diabetes.*

*Please tell us if you are currently undergoing treatment or taking medications for any of the following. Select all that apply, and if you write in another complication, please be sure to click “Yes” next to it.*

- Eye problems (other than basic vision/glasses not related to diabetes)
- High blood pressure
- Heart/circulation problems
- Kidney problems

- Cholesterol problems
- Nerve damage
- Arthritis
- Depression
- Other
- I'm not undergoing treatment or taking medications for any of these health complications

#### Question 9

*Please tell us what range your A1c result falls in.*

- 5 or lower
- 5.1 to 5.5
- 5.6 to 6
- 6.1 to 6.5
- 6.6 to 7
- 7.1 to 7.5
- 7.6 to 8.0
- 8.1 to 8.5
- 8.6 to 9.0
- 9.1 to 9.5
- 9.5 to 10.0
- 10.1 or higher

#### Question 10

*From your personal perspective, what do you consider to be the five biggest barriers to better diabetes management? Please rank the five biggest barriers below.*

BIGGEST barrier

SECOND biggest barrier

THIRD biggest barrier

FOURTH biggest barrier

FIFTH biggest barrier

- Drop down choices: Cost of medications and devices and care; Managing the number of pills and/or insulin doses you have to take each day; Side effects from diabetes medications (for example, hypoglycemia, weight gain, etc.); Lack of adequate training on taking medications and using devices; Drug and medication device labeling that is not clear or easy to understand; Not being able to find a combination of medications that works for you personally; Stress involved in managing diabetes; Difficulty sticking to diet and exercise; Lack of support from those around me (friends, family, work); Stigma associated with diabetes; Fear surrounding diabetes

#### Question 11a

*Some people take medications 'off-label' for their diabetes. This means that under the care of a healthcare team, they take medications that are not approved by the FDA either for diabetes, or their particular type of diabetes.*

*Do you take any medications 'off-label'?*

- Yes
- No

- Not sure/don't know
- Prefer not to say

#### Question 11b

*What medications are you currently taking 'off-label'?*

- Open-ended

#### Question 12a

*How old were you when you were first told you had diabetes?*

- Open-ended

#### Question 12b

*How old are you now?*

- Open-ended

#### Question 13

Please tell us how having diabetes impacts your life when it comes to the following:

Success at work or school

Relationships with co-workers or fellow students

Family relationships

Building and maintaining friendships

Dating and romance

Intimacy/sexual relationships

Self-confidence

Ability to take on life's challenges

Planning for the future

Other

- Selections for each area: Serious negative impact; Mild negative impact; No negative impact; Does not apply to me; Prefer not to answer

#### Question 14

*Other than a complete cure, please tell us in your own words what a new medication or technology for people with diabetes could most usefully do for you today.*

- Open-ended

#### Question 15

*Finally, how did you hear about this survey?*

- ADA
- JDRF
- diaTribe
- FDA
- Other (please specify)

#### Question 16

*That's the end of the survey. If you have other comments about the questions you have just answered or about diabetes in general, please write them here. Otherwise please remember to click 'NEXT' to submit your answers.*

*Thank you so much for completing this survey. You are helping bring patient voices to the FDA, which is so important, and for which we are very grateful.*